

EUROPEAN
ORGANISATION
FOR RARE DISEASES

eurordis.org

FINANCIAL

REPORT



EURORDIS
Rare Diseases Europe

2014

“ The Voice of Rare Disease Patients in Europe ”

Foreword of the Treasurer

Throughout the last few years, patients' involvement has increased, both at national and international level. This involvement has also had its financial impact and can be measured on the "volunteers" budget line, which has increased steadily over the past 5 years. During this period the "Volunteers" budget line has almost doubled.

The growth in patient involvement is also apparent through a greater participation in EU funded projects. EURORDIS is currently involved in 7 Projects implementing different financial means (operating grant, conference grant, research projects, joint action, tendering contract) with 3 EU institutions (DG Health and Food Safety; DG Research and Innovation; the Innovative Medicine Initiative Joint Undertaking).

The growth of EURORDIS as an organisation as well as the impact that its activities have within the Rare Disease Community can be seen in the widening of EURORDIS membership with currently 646 members from 60 countries. There was also an increase in the number of the countries participating in the Rare Disease Day, reaching 84 in 2015. Expanding was also the number of regulatory dossiers studied for rare disease treatments, reaching 456 in 2014; as was the number of patient advocates engaged through EURORDIS in scientific advice or HTA and the number of participants at the EURORDIS Membership Meetings, or Summer Schools or the European Conference on Rare Diseases & Orphan Products.

As every year it has been extremely challenging to balance the budget, but at the very end of the year we were presented with some good news which allowed us to increase our reserves.

We hope and believe that in 2015 EURORDIS will continue to preserve its ability to help provide support for the ever growing and demanding more and more challenging needs of patients with Rare Diseases and expand its activities in order to take advantage of the opportunities we are generating. The budget is at the same time ambitious and realistic. It also complies with our rules vis à vis potential conflict of interest with the health sector industry, while progressively further diversifying towards other private and public funding.

Dimitrios Synodinos / Treasurer

EURORDIS

Association governed by the French law of July 1, 1901

96, rue Didot
75014 PARIS

STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2014

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Association governed by the French law of July 1, 1901

96, rue Didot
75014 PARIS

STATUTORY AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS

Year ended December 31, 2014

In compliance with the assignment entrusted to us by the Members' meeting, we hereby report to you, for the year ended December 31, 2014, on :

- the audit of the accompanying financial statements of the EURORDIS Association,
- the justification of our assessments,
- the specific procedures and disclosures required by law.

These financial statements have been approved by the Association's Board of Directors. Our role is to express an opinion on these financial statements, based on our audit.

I. Opinion on the financial statements

We conducted our audit in accordance with professional practice standards applicable in France. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, using sample testing techniques or other selection methods, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made, as well as evaluating the overall financial statement presentation. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

In our opinion, the financial statements give a true and fair view of the EURORDIS Association's financial position and its assets and liabilities as of December 31, 2014 and the results of its operations for the year then ended, in accordance with French accounting regulations.

Société anonyme au capital de 1 723 040 €
Société d'Expertise Comptable inscrite au Tableau de l'Ordre du Conseil Régional de Paris Ile-de-France
Société de Commissaires aux Comptes, membre de la Compagnie régionale de Versailles
572 028 041 RCS Nanterre
TVA : FR 02 572 028 041

Member of Deloitte Touche Tohmatsu Limited

Without qualifying our opinion, we draw your attention to the matter set out in the notes “Significant events of the year”, and “retirement allowance” to the financial statements that expose the change in method relating to allowances retirement, accrued as of fiscal year 2014:

- For an amount of € 24,814 on 1st January 2014 charged to equity.
- For a total of € 37,807 to 31st December 2014 by an additional allocation of € 12,993.

II. Justification of assessments

Pursuant to the provisions of Article L.823-9 of the French Commercial Code on the justification of our assessments, we hereby inform you that our assessments covered the accounting policies implemented by your Association. We have verified the appropriateness of these accounting policies and the disclosures in the Notes.

The assessments on these matters were performed in the context of our audit approach for the financial statements taken as a whole, and therefore contributed to the opinion we expressed in the first part of this report.

III. Specific procedures and disclosures

We have also performed the other procedures required by law in accordance with professional standards applicable in France.

We have no comment to make as to the fair presentation and consistency with the financial statements of the information given in the Board of Directors’ financial report and in the documents addressed to the Members with respect to the financial position and the financial statements.

Neuilly-sur-Seine, May 11, 2015

The Statutory Auditor

Deloitte & Associés

Philippe GUAY

This is a free translation into English of the original Statutory Auditor’s report issued in the French language and is provided solely for the convenience of English-speaking readers. This report should be read in conjunction and construed in accordance with French law and professional auditing standards applicable in France.

Assets	2013	2014	Ratio	Difference
FIXED ASSETS				
Intangible assets	206	0	-100%	-206
Tangible assets	59 800	49 752	-17%	-10 049
Financial assets	4 249	3 917	-8%	-332
TOTAL	64 255	53 669	-16%	-10 586
CURRENT ASSETS				
Account receivable due within one year	1 273 897	1 080 900	-15%	-192 997
Account receivable due after one year	638 328	567 049	NA	-71 279
Liquid assets	1 433 419	806 268	-44%	-627 151
Prepaid expenses	58 940	48 420	-18%	-10 519
TOTAL	3 404 584	2 502 637	-26%	-901 947
TOTAL ASSETS	3 468 839	2 556 306	-26%	-912 533

Liabilities	2013	2014	Ratio	Difference
ASSOCIATION FUNDS				
Reserve	633 193	625 736	-1%	-7 457
Profit & loss for the year	17 357	199 835	1051%	182 478
Subsidies of investment	0	0	NA	0
TOTAL	650 550	825 571	27%	175 021
Provisions for risk and charges	116 956	37 807	-68%	-79 149
Dedicated funds on grants	0	0	NA	0
DEBTS				
Bank loans and overdraft	0	0	NA	0
Trade creditors	155 045	173 341	12%	18 296
Tax payable and social liabilities	269 154	266 857	-1%	-2 297
Other debts	29 364	29 364	0%	0
Deferred income within one year	1 419 428	619 341	-56%	-800 086
Deferred income after one year	828 343	604 026	-27%	-224 318
TOTAL	2 818 289	1 730 736	-39%	-1 087 554
TOTAL LIABILITIES	3 468 839	2 556 306	-26%	-912 533

**2014 Financial Status VS.
2013 Financial Status**
(Profit and Loss including in kind contributions)

Revenue	2013 Fin. Status	2014 Fin. Status	Ratio	Δ in euros	Δ in %
Patient Organisations	839 604	889 922	19%	50 319	6%
Financial contributions	634 500	674 196	15%		
<i>AFM-Téléthon</i>	634 500	634 500	14%		
<i>Other Members</i>		39 696	1%	39 696	
In kind contributions (AFM)	172 746	172 746	4%		
Membership fees	32 358	42 980	1%	10 623	33%
Individuals	696 297	829 963	18%	133 666	19%
Volunteers	691 697	823 876	18%	132 179	19%
Donations	4 601	6 087	0%	1 486	32%
European Commission	1 101 444	1 358 072	29%	256 628	23%
DG Research & Innovation	221 422	246 980	5%	25 558	12%
DG Health & Food Safety	831 576	1 042 230	22%	210 654	25%
European Medicines Agency (*)	48 445	68 862	1%	20 417	42%
National authorities	16 061	22 961	0%	6 900	43%
Grants from National authorities	16 061	22 961	0%	6 900	43%
Corporates	1 076 699	1 195 979	26%	119 280	11%
Pharma. and Biotech Companies	1 007 187	1 073 156	23%	65 969	7%
Other Health Sector Corporates	18 000	30 405	1%	12 405	69%
Outside Health Sector Corporates	51 512	92 418	2%	40 905	79%
Not for Profit Organisations	183 823	50 694	1%	-133 129	-72%
Pharma. and Biotech Found.					
Other Health Sector NPOs	148 823	50 694	1%	-98 129	-66%
Outside Health Sector NPOs	35 000			-35 000	
Event Fees	34 104	218 774	5%	184 671	541%
Miscellaneous	47 259	68 877	1%	21 618	46%
Reimbursement	16 542	22 534	0%	5 992	36%
Financial assets	20 871	19 782	0%	-1 089	-5%
Exceptional income	9 846	26 561	1%	16 715	170%
Sub-total	3 995 290	4 635 242	100%	639 952	16%
Recovery of provisions	44 973	116 956		71 983	160%
Report of non-used income					
Total Revenue	4 040 263	4 752 198		711 935	18%

Expenses	2013 Fin. Status	2014 Fin. Status	Ratio	Δ in euros	Δ in %
Staff	1 984 262	2 006 444	44%	22 182	1%
Wages and charges	1 906 260	1 933 063	43%	26 803	1%
Other salaries	64 243	64 229	1%	-15	0%
Training and other costs	13 759	9 153	0%	-4 606	-33%
Volunteers	691 697	823 876	18%	132 179	19%
Representative and task forces	567 091	674 395	15%	107 303	19%
Project, office and translators	124 606	149 482	3%	24 876	20%
Travel and subsistence	443 631	424 575	9%	-19 056	-4%
Travels and subsistence	395 185	355 713	8%	-39 473	-10%
In kind contribution (*)	48 445	68 862	2%	20 417	42%
Services	807 936	1 181 964	26%	374 028	46%
Fees	275 691	437 134	10%	161 442	59%
Event logistics and catering	179 721	365 963	8%	186 242	104%
Telecom and post	44 777	45 457	1%	680	2%
Rent	218 702	221 108	5%	2 407	1%
Other services	89 045	112 302	2%	23 257	26%
Purchase	83 936	92 910	2%	8 975	11%
Office furniture	13 785	19 500	0%	5 715	41%
Amortization	23 290	21 459	0%	-1 830	-8%
Communications, Publications	39 641	31 840	1%	-7 802	-20%
Other purchases	7 219	20 111	0%	12 892	179%
Miscellaneous	11 445	9 601	0%	-1 844	-16%
Sub-total	4 022 906	4 539 370	100%	516 464	13%
Contingency and loss provisions		12 993	0%	12 993	
Commitment on assigned income					
Total Expenses	4 022 906	4 552 363		529 457	13%
Result	17 357	199 835			

* covering travel/accommodation costs for EMA meetings

2014 Financial report comments

Two significant facts in the 2014 financial status:

1. Decrease of the
 - a. Assets and Liabilities accounts by 913k€
 - b. Liquidities by 627k€
2. Increase of the
 - a. Profit and Loss accounts by 640k€ before provisions
 - b. Association Funds by 175k€

The organisation of the European Conference for Rare Diseases partly explains the increase of the Profit and Loss accounts.

The rest of these significant variations are due to events over which EURORDIS had no control. Even if it was not forecasted, the increase of our Association funds by 175 k€ is good news: it is the only way to absorb the unexpected.

1. Assets and Liabilities

1.1. Assets

Current assets decreased from 3 405 k€ to 2 503 k€.

	2013	2014	Difference	
Accounts receivable	1 912 226	1 647 949	-264 276	-14%
Liquid assets	1 433 419	806 268	-627 151	-44%
Prepaid expenses	58 940	48 420	-10 519	-18%
Total	3 404 584	2 502 637	-901 947	-26%

Usually, the Operating Grant from DG Health and Food Safety (DG SANTE) is signed and the first instalment is transferred before the end of the year preceding the start of the contract. In 2013, DG SANTE changed its processes and because of IT issues on the European Commission (EC) side, the signature and pre-financing of this grant (amounting to 770k€) was postponed to the start of 2015. This is the reason of the severe decrease of the Assets and Liabilities.

As a general conclusion, the Assets decrease is not caused by a structural change in our funding but by a short term delay which has been solved in the meantime and which could be absorbed thanks to our reserves.

1.1.1. Accounts receivable

Accounts receivable are monies to be received in the context of grants when an agreement has been signed and the cash has not yet been transferred.

The bulk of this line comes from the European Commission (1 469 k€, 91%) and co-funders (111 k€, 7%) of EC grants.

1.1.2. Liquid assets

Liquid assets are cash in the bank. The decrease of cash comes from the absence of the first instalment of the Operating Grant 2015. It was finally transferred in February 2015.

1.2. Liabilities

1.2.1. Association Funds

Association funds are the reserve which is the sum of all surplus / deficit since the creation of EURORDIS. At the end of 2013, the reserve amounted to 651k€, which means an average surplus of 38 k€ every year since 1997. In 2014, the surplus exceptionally amounted to 200 k€. Therefore, the reserve increased from 651 k€ to 851 k€, signifying a 31% increase.

In 2014, this amount has been reduced by 25 k€ because of a change of accounting method in 2014: we decided to record a provision for retirement benefits. It is a skilful calculation which allows to put aside the amount that we will have to be paid when people will retire.

Due to this change in accounting method, the amount that we would have calculated in 2013 needs to be transferred from the reserve to the provisions (25 k€).

1.2.2. Provisions

Provisions on ongoing contracts

In 2009, the Executive Agency for Health and Consumers (EAHC), which is now called the Consumers, Health, Agriculture and Food Executive Agency (CHAFAEA) mandated an audit of the RAPSODY project that ended in 2008. The total of the finding amounted to EUR 5 175 which have been refunded in 2014.

Forecasted loss on EUCERD Joint Action

In 2013, there was a risk that this action could not be funded by the European Commission because of uncertainties around budget transfers between partners. At the start of 2015, this question has been solved and we also know that the money raised in the context of the EURORDIS Gala Dinner 2015 will cover the co-funding. Therefore, we had to recover the entire provision (112 k€) at the end of the closing of the accounts in February 2015 (first reason why we have a surplus amounting to 200 k€).

Provision for retirement benefits

Please see 1.2.1. above, paragraphs 2 & 3.

	2013	2014		
		Recoveries	New provisions	Balance
Provisions on ongoing contracts	5 175	-5 175	0	0
Forecasted loss on EUCERD Joint Action	111 782	-111 782	0	0
Provision for retirement benefits	24 814	0	12 993	37 807
Provisions for risks and charges	141 771	-116 957	12 993	37 807

1.2.3. Trade creditors

2013	155 k€	4%
2014	173 k€	7%
difference	+ 18 k€	12%

Trade creditors are monies to be paid to suppliers for invoices that have been received (or to be received) and have not been paid yet. The situation at the end of 2014 was average compared to previous years.

1.2.4. Deferred income

2013	2 248 k€	65%
2014	1 223 k€	48%
difference	- 1 024 k€	-56%

Deferred income refers to the part of grants concerning the incoming years (the part of the grant that has not been consumed yet). This is different from the account receivable which concerns the cash flow whereas the calculation of the deferred income is based on the expenses that occurred in the context of the action. The calculation of the grant is a percentage of direct costs + a percentage of overheads. These percentages differ from one contract to another.

Deferred income (1 223 k€) is abnormally low at the end of 2014.

This is due to the absence of signature of Operating Grant for 770 k€ (please see 1.1. Assets) and also to the fact that no new significant pluri-annual contract has been signed in 2014.

It is mainly composed of the pluri-annual EC projects (996 k€, 81%) and correlated co-funding (143 k€, 12%).

2. Revenue

The revenue including in-kind contributions and excluding recovery of provisions amounted to 4 635 k€. This represents an increase of 640 k€ (+ 14%) compared to 2013.

This increase is mainly due to

- the European Conference on Rare Diseases (ECRD 2014 Berlin, +285 k€)
- the increase of the Operating Grant DG SANTE (+189 k€)
- the increase of the volunteers (+132 k€)

The breakdown of EURORDIS' revenue by sources is as follows:
(amounts are in thousands of euros, recovery of provisions are excluded¹)

	2013 Fin. Status		2014 Fin. Status		Difference	
AFM	807	20%	807	17%	0	0%
Membership fees and grants	32	1%	83	2%	50	61%
Individuals(incl. Volunteers)	696	17%	830	18%	134	16%
Patient Org. and Individuals	1 536	38%	1 720	37%	184	11%
European Commission	1 101	28%	1 358	29%	257	19%
National authorities	16	0%	23	0%	7	30%
Pharma. and Biotech Companies	1 007	25%	1 073	23%	66	6%
Other Health Sector Corporates	18	0%	30	1%	12	41%
Health Sector Corporates	1 025	26%	1 104	24%	78	7%
Other Corporates	52	1%	92	2%	41	44%
Foundations and NPOs	184	5%	51	1%	-133	-263%
Event fees	34	1%	219	5%	185	84%
Others	47	1%	69	1%	22	31%
Total	3 995	100%	4 635	100%	640	14%

Overall: 37% of resources are contributed by our members and individuals, 29% from European Commission and Member States, 24% by Health Sector Corporates, 5% from Event fees (ECRD 2014 Berlin) and 5% from other private resources.

The proportion of funding by source fully complies with our *Policy on Financial Support by Commercial Companies*²: the level of revenues from Health Sector Corporates represents 24% and is contributed by 47 different companies. It does not exceed the amount of revenues from Patient Organisations and volunteers (37%).

More details on revenues:

2.1. Patient Organisations and Individuals

2013	1 536 k€	38%
2014	1 720 k€	37%
difference	+ 184 k€	+ 11%

¹ Recovery of provisions is excluded from this table in order to better analyse the evolution of the revenue by the source of funding. For more information, please see 1.2.2. Provisions above.

² for more details on policy and financial structure, see www.eurordis.org

Since EURORDIS' creation and up to 2012, AFM-Téléthon was EURORDIS' largest donor. In 2013, the addition of all grants from the DG SANTE of the European Commission (through its agency CHAFEA) amounted to 832 k€ compared to 807 k€ from AFM-Téléthon.

In 2014,

- the grants from DG SANTE increased from 832 k€ to 1 042 k€
- the economic valorisation of volunteers increased from 692 k€ to 824 k€
- and the AFM-Téléthon grant remained stable at 807 k€

Overall, the ratio from the Patient Organisation's sector remains the highest.

2.1.1. Association Française contre les Myopathies (AFM – Téléthon)

2013	807 k€	20%
2014	807 k€	17%
Difference	0 k€	0%

The AFM-Téléthon grant enables us to maintain the independence of EURORDIS for its core activities while using this financial support as leverage to develop and diversify our sources of revenue.

In the framework of the 2011-2014 AFM-Téléthon/EURORDIS agreement, the purpose of this grant is focused on core operations (governance, membership, advocacy, therapeutic development, management). It is our best guarantee of independence with respect to public institutions and commercial companies.

In 2014, it amounted to 635 k€ which was equal to 2013. We are very grateful to all AFM-Téléthon donors: without all these individual gifts, EURORDIS would not be able to leverage the funds that enable us to conduct our advocacy activities with no conflict of interest with both the private-for-profit sector and public institutions.

In addition to the money granted, the AFM-Téléthon provides us with office space for our Paris-based staff at the Rare Disease Platform. The valorisation of this in-kind contribution is based on statistics that will be updated every third year.

2.1.2. Individuals

2013	696 k€	17%
2014	830 k€	18%
Difference	+ 134 k€	+ 16%

In 2014, we decided to group the amount originating from the economic valorisation of volunteers together with the donations from individuals (even if this amount is still very modest compared to the impressive amount of hours donated by our volunteers).

The dedication of our volunteers is still growing. In 2014, their work represented 8 full time equivalents (fte), a total amount of more than 13,000 hours.

Time spent by volunteers is validated by the volunteer him/herself (> 90%) or estimated by project managers (< 10%). The overall process is validated by our auditors.

We need to repeat again that volunteers are an irreplaceable way of representing patients living with a rare diseases throughout Europe thanks to their diversity of experience, skills and background.

They mainly work on matters pertaining to public affairs (4 fte), orphan medicinal products (1.9 fte) and moderation of the rareconnect.org website (1.8 fte).

2.2. European Commission

2013	1 101 k€	28%
2014	1 358 k€	29%
Difference	+ 257 k€	+ 19%

EURORDIS currently runs nine different grants from DG SANTE, DG RESEARCH and IMI-JU³.

In addition to

- the DG SANTE Operating Grant (which has been renewed every year since 2009);
- the DG SANTE, DG RESEARCH and IMI-JU Grants started in 2013 (EUCERD Joint Action, ECRIN, RD-CONNECT, EUPATI);
- the DG RESEARCH Grant started in 2014, RARE-Bestpractices;
- the ECRD 2014 DG SANTE grant started in 2014;

EURORDIS is the beneficiary of two new projects:

- Web-Radr, from IMI-JU
- Genetic Clinic of the Future, from DG RESEARCH

Also, a Framework Partnership Agreement has been signed with DG SANTE for 2015-2017. This is a three years contract for the Operating Grant. EURORDIS has repeatedly requested a multi-year contract because the amount of the renewal was advertised at some point from July to September of the year preceding the grant.

If an external evaluator decided that EURORDIS should not be renewed, it would be dramatic because the amount of the grant is greater than the reserves and almost all staff is permanent.

For this reason, it is a relief that it is a three year contract.

However, the amount is fixed for the upcoming year only and theoretically, there is no minimum amount. It means that DG SANTE could decide to grant us with a 20 k€ contract instead of 770 k€ from one year to another.

2.3. National authorities

2013	16 k€	0%
2014	23 k€	0%
Difference	+ 7 k€	+30%

³ IMI-JU is a Joint Undertaking between DG Research and the European Federation of Pharmaceutical Industries and Associations (EFPIA) called "Innovative Medicine Initiative". In the budget, the contribution from EC (82%) is recorded under chapter "DG Research" and the contribution from EFPIA companies through a "cash pot" collected and redistributed by the coordinator (European Patient Forum - EPF) under the chapter "Other Health Sector NPOs".

This line is a part of the co-funding of the EUCERD Joint Action by the “Caisse Nationale de Solidarité pour l’Autonomie” (25 k€ per year for 3 years). It funds 21% of the costs incurred in the context of the Work Package 6 “Specialised Social Services”, hence the variation of the amounts from one year to another.

2.4. Health Sector Corporates

2013	1 025 k€	26%
2014	1 104 k€	24%
Difference	79 k€	+ 6%

This line comprises 43 pharmaceutical companies and 4 health sector consulting firms.

The level of contribution from the Health Sector Corporations remains stable<

The increase comes from:

- the EURORDIS Round Table of Companies (ERTC), the income for which has been constantly increasing since 2008
- an unrestricted grant of 50 k€ which we received in December 2014 and which was not expected (second reason why we have a surplus amounting to 200 k€).

Other pharmaceutical companies support the EURORDIS Membership Meeting, the RareConnect project and the EURORDIS Black Pearl Gala Dinner.

The five largest donors are, in descending order: SHIRE, GSK, CELGENE, CSL BEHRING and PFIZER.

The percentage of each of the 47 companies in the overall budget comprises between 0.05% and 2.13%.

The two guarantees of our independence with this sector are (1) the limitation of the overall amount compared to income of Patient Organisation provenance and (2) the diversity and limited impact of each single donor.

2.5. Other Corporates

2013	52 k€	1%
2014	92 k€	2%
difference	+ 40 k€	+79%

It is the third year that EURORDIS succeeds in raising funds from corporations which are not dedicated to the health sector. This funding has been proceeded through in kind services from

- DLA Piper UK LLP for legal services,
- Burson-Marsteller and Multiburo, two companies based in Brussels,
- S.I.A.R.C. Societa Iniziative Artistiche e Culturali (Di Carlo Hintermann & Company),
- MediaPlanet, DaRen,

as well as a contribution from Ares Life Sciences, an investment partnership.

2.6. Foundations and Not for Profit Organisations (NPOs)

2013	184 k€	5%
2014	51 k€	1%
difference	-133 k€	-263%

In 2014, the French Pharmaceutical Union (LeeM) and the Medtronic Foundation did not support EURORDIS. The Fundació Doctor Robert had to stop offering EURORDIS in-kind office space and the Everylife Foundation did not donate to the Gala 2014.

Thanks to AIPM and the co-funding of EFPIA in the context of the IMI-JU EUPATI project, this section is still alive.

2.7. Event Fees

2013	34 k€	1%
2014	219 k€	5%
difference	+ 185 k€	+544%

In 2013, in absence of an ECRD, Event fees consisted of EURORDIS Black Pearl Gala Dinner seats and EURORDIS Membership Meeting in Dubrovnik.

In 2014, the 7th European Conference on Rare Diseases in Berlin (ECRD 2014 Berlin) was co-organised with the Drug Information Association (DIA) and explains the significant increase of Event fees.

3. Expenses

Operating expenses, including in-kind contributions and excluding provisions, amounted to 4 539 k€, which shows an increase of 11% compared to 2013.

The increase is due to:

- ECRD 2014 Berlin (+284 k€)
- Volunteers (+132 k€)

The breakdown of EURORDIS expenses is as follows
(in thousands of euros, provisions excluded⁴)

Expenses	2013 Fin. Status		2014 Fin. Status		Difference	
Staff costs	1 984	49%	2 006	44%	22	1%
Volunteers	692	17%	824	18%	132	16%
Travel and subsistence	444	11%	425	9%	-19	-4%
Services	808	20%	1 182	26%	374	32%
Others	95	2%	103	2%	7	7%
Total	4 023	100%	4 539	100%	516	11%

⁴ Recovery of provisions is excluded from this table in order to better analyse the evolution of the revenue by the source of funding. For more information, please see 1.2.2. Provisions above.

More details on expenses:

3.1. Staff costs

2013	1 984 k€	49%
2014	2 006 k€	44%
difference	+ 22 k€	+ 1%

The number of FTE⁵ was 28 in 2014.

A new long term position was created in 2014: Research and Healthcare Director held by Matt Johnson.

Altogether, at the end of the year, we were 35 staff members comprising:

In Paris: 21 permanent employees, one office volunteer, one limited contract, 3 trainees, 1 staff in parental leave;

In Brussels: 3 permanent employees;

In Barcelona: 3 permanent employees;

In Geneva: 1 permanent employee;

In London: one staff seconded to the European Medicines Agency.

3.2. Travel and subsistence

2013	444 k€	10%
2014	425 k€	9%
difference	-19 k€	-4%

Travel and subsistence costs were mainly incurred in the context of:

- ECRD 2014 Berlin (51 k€) + Membership meeting (9 k€) + Fellowships (16 k€)
- Attendance to the European Medicines Agency + meetings of task forces (32 k€),
- Summer School (31 k€)

3.3. Services

2013	808 k€	20%
2014	1 182 k€	26%
Difference	+ 374 k€	+ 46%

Services were allocated as follows:

ECRD 2014 Berlin	20%
In kind Paris office renting from AFM	15%
RareConnect	9%
National Plans (EUCERD Joint Action)	7%
Rare Disease Day	7%
EURORDIS Gala Dinner	6%

The remainder is dispatched on 20 other activities.

⁵ 1 full time equivalent = 1 people on a full time position during one year

4. Result

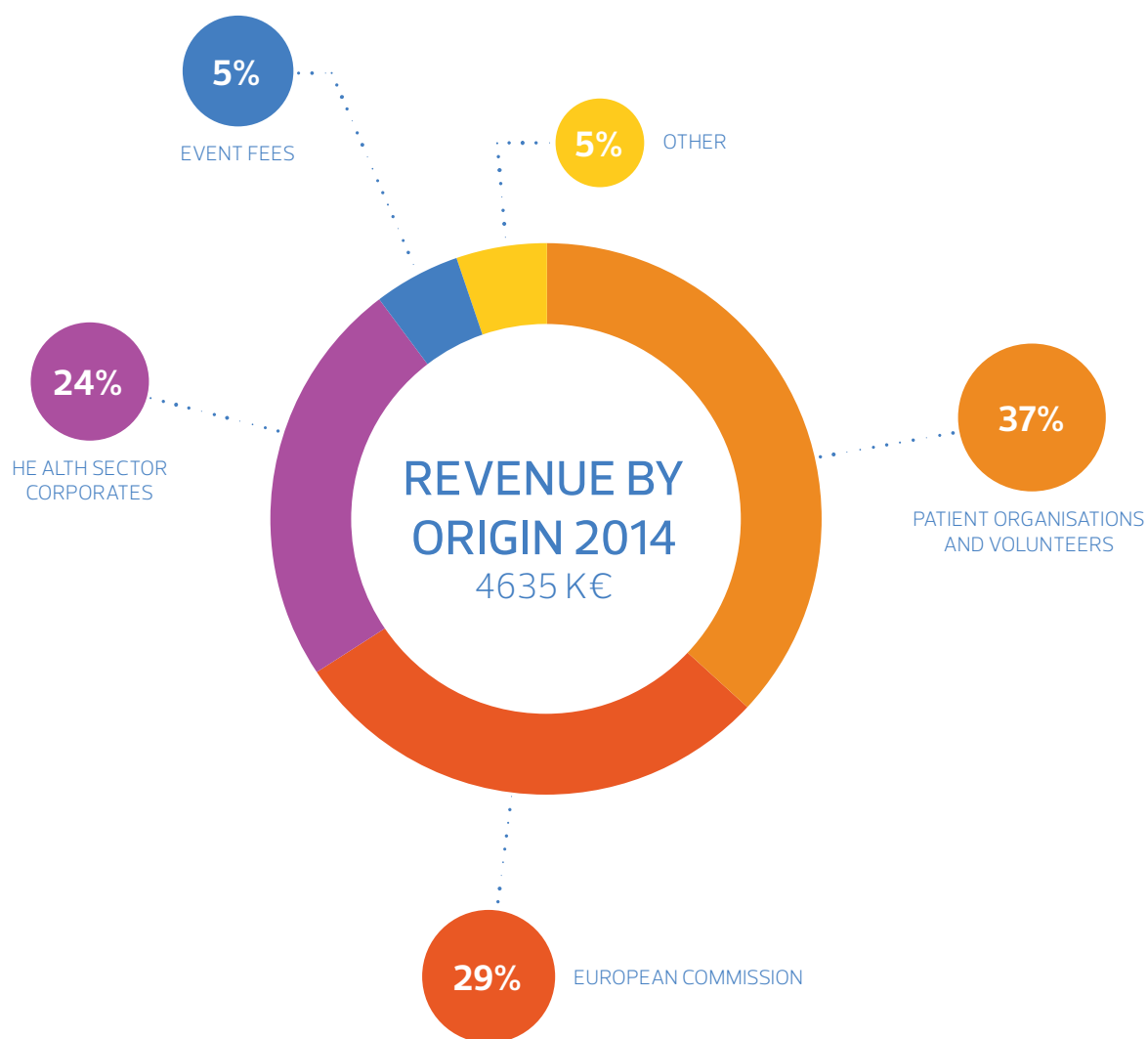
For the unexpected reasons detailed above (last minute decision on budget transfer in the context of the EUCERD Joint Action in February 2015 (impact of 112 k€) + last minute unrestricted grant of 50k€ signed in December for 2014), the 2014 surplus amounted to EUR 199 835 and we suggest to allocate it to the reserve.

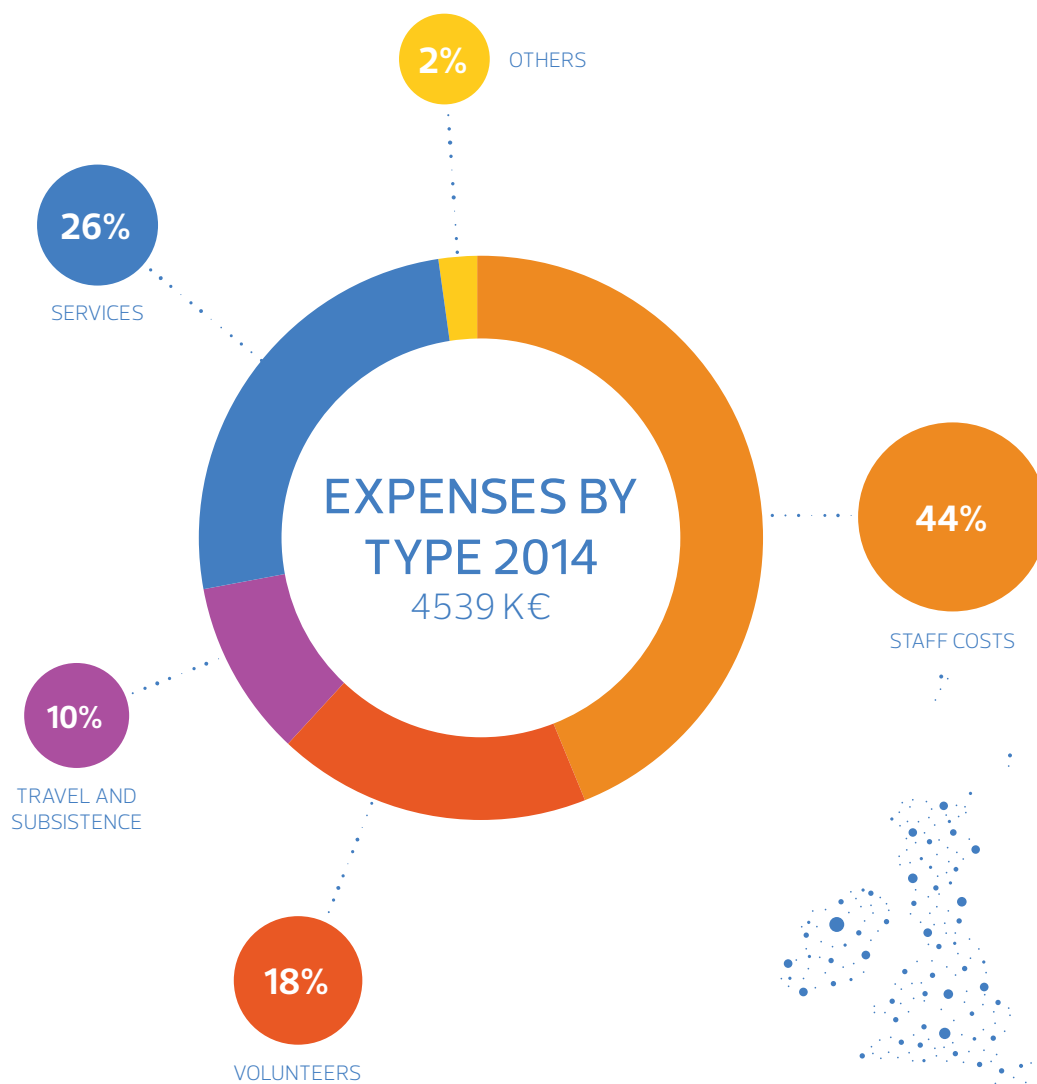
Because of the transfer to the provisions for retirement benefits the increase of the reserve is reduced by EUR 24 814. The association funds will amount to EUR 825 571 which will represent 4 months of low-level activity.

If we refer to EURORDIS' policy, which is to have reserves representing from 3 to 6 months of low-level activity, the situation is not totally comfortable but it is safe enough.

REVENUE & EXPENSES

2014





Glossary

AFM-Téléthon: Association Française contre les Myopathies. Created and organises the French Téléthon.

EC: European Commission

DG SANTE: Health and Food Safety Directorate-General of EC

Ongoing Projects:

- *EURORDIS FY2014* (2014 Operating Grant)
 - o from 01-Jan-14 to 31-Dec-14
- *EJA* (EUCERD Joint Action: Working for Rare Diseases)
 - o from 01-Mar-12 to 31-Aug-15
 - o EURORDIS is co-beneficiary
- *ECRD 2014* (European Conference on Rare Diseases & Orphan Products 2014)
 - o from 01-Jan-14 to 31-Aug-14
 - o EURORDIS is co-beneficiary

DG RESEARCH: Research and Innovation Directorate-General of EC

Ongoing Projects:

- *ECRIN IA* (European Clinical Research Infrastructures Network)
 - o from 01-Jan-12 to 31-Dec-15
 - o EURORDIS as co-beneficiary
- *RD Connect* (An integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research)
 - o from 01-Nov-12 to 30-Oct-18
 - o EURORDIS as co-beneficiary
- *RARE-Bestpractices* (A platform for sharing best practices for the management of rare diseases)
 - o from 01-Jan-13 to 31-Dec-16
 - o EURORDIS as co-beneficiary
- Genetic Clinic of the Future (A stepping stone approach towards the Genetics Clinic of the Future)
 - o from 01-Dec-14 to 31-May-17
 - o EURORDIS as co-beneficiary

IMI-JU Innovative Medicine Initiative, a DG RESEARCH / EFPIA Joint Undertaking

- *EUPATI* (European Patients' Academy on Therapeutic Innovation)
 - o from 01-Jan-12 to 31-Dec-16
 - o EURORDIS as co-beneficiary
- *Web-Radr* (Recognising Adverse Drug Reactions)
 - o from 01-Sep-14 to 31-Aug-17
 - o EURORDIS as co-beneficiary

ECRD: European Conference on Rare Diseases.

7 of them already taken place

ECRD 2014, in Berlin (co-organised by EURORDIS and DIA)
ECRD 2012, in Brussels (co-organised by EURORDIS and DIA)
ECRD 2010, in Krakow (organised by EURORDIS and partners)
ECRD 2007, in Lisbon (organised by EURORDIS and partners)
ECRD 2005, in Luxembourg (organised EURORDIS and partners)
ECRD 2003, in Evry (France, organised by Alliance Maladies Rares)
ECRD 2001, in Copenhagen (organised by Rare Disorders Denmark)
The eighth will take place in May 2016 in Edinburgh.

EMA: European Medicines Agency

EUCERD: European Union Committee of Experts on Rare Diseases



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